Chapter 11

Environment and Context

Nobody lives in a vacuum. We are constantly responding and interacting to people, places, things and events around us. Environments represent the integration of these factors. The environments where we work, live and love are just as dynamic and just as complex as our brains and our bodies. They are constantly changing. People come and go, locations change, goals and expectations change, and the tools and resources available to us also change. The effects of such changes can be profound, whether or not we have a brain injury.

Environmental Factors

Let’s first consider studies conducted on the effects of job loss in small communities where disability is not the issue.

Example of environmental change:

Researchers have repeatedly found that after a primary employer leaves a small town, there are dramatic increases in physical illness, disease, drug and alcohol use, depression and other emotional disorders. There are also dramatic increases in suicide attempts, family break-ups, problems in schools, increases in crime, and other major trauma. People’s behavior changes dramatically when the context and fabric of their lives are altered. In these situations, the daily rules of life have changed and nobody is certain what the new rules are.

Think about how your behavior changes when your environment substantially changes. This can occur when starting a new job, moving to a new town, starting or ending a significant relationship, or even setting new goals for yourself. At first, you may be unsure and feel less competent or capable than you were in your old situation. It takes time to learn the ins and outs of a new employer. You probably get lost when first trying to find your way around your new town and don’t yet know all the best places to shop. It takes time to make new friends and establish social networks. You may find yourself making social blunders as you learn the local customs and nuances of your new community.

Now, consider what occurs when someone experiences significant disability following a brain injury and everything is thrown out the window. Environmental factors play a very important role in innumerable ways for the individual, other people, places and purpose.

Individual

We’ve already covered the medical and neurological consequences of injury in some detail as well as a person’s history. But these alone don’t fully account for behavioral changes that occur. It is critical to consider how this person who may now think, hear, see, remember, move and understand differently responds to events in their environment. As noted earlier in the book, if your vision has changed and you are reacting to what you see, you will probably behave differently because you have different visual information. Ditto for hearing, thinking, and so on. The processes by which you behave may not have changed, but your behavior will change because you are responding to “new” or different information.

The manner in which a person analyzes this information is also important. Some people don’t have the capacity to recognize such changes and continue to act as before. However, most people often fall back on previous patterns of behavior when facing new or unfamiliar situations or experiences. We usually try to compare the new situation to past experiences and respond accordingly. We often emotionally respond to new circumstances based on what we perceive as similar past experiences. That’s why a person’s history, preserved skills and
past behavioral patterns are so important to consider. A person who is acting fearful or anxious may be responding in part to something that happened to them previously. The current situation is a reminder of it. The individual may be stuck in this pattern until the issue is addressed.

Conversely, a person may successfully transition into a new experience or task because there is a balance between present strengths and a history of positive and successful experiences making changes. In essence, the “person part” of this equation involves present and historical (preserved) skills, abilities, and experiences that the individual brings to the situation. Much like a key (the person) and a lock (the environment), the match or mis-match between these factors will determine success (opening the door) or failure (continued barriers and frustration).

People
As we’ve already noted, other people’s personal reactions and interactions can also change. Some people “simply” fade away. Other people’s behavior and relationship to the individual with a disability changes as their roles and responsibilities change. This can be good or bad news depending on the nature of the people and relationships that remain involved. Unfortunately, as noted in previous chapters, far too often it is the absence of people that is the problem.

Places
A person’s actual physical environment may also have changed. The person may be living in a different house or apartment, participating in a treatment program, or may be homeless, in jail, or in some place that is socially, physically and culturally different from a previous residence. The physical design of where the person lives can affect a person’s ability to function independently or require assistance in daily activities. For example, a person who has trouble walking and lives in a two-story house will likely require more help to meet daily needs than if living in a house that is physically accessible. Lack of reasonable transportation will cut off other opportunities or make simple daily chores intolerable. Living in a rural area, in the “middle of nowhere” may mean that a person is less likely to get in trouble with “the wrong crowd.” But a person is also less likely to have regular access to a variety of daily activities due to the remote location. Contrast this with a person who lives in the city where there may be more opportunities for social interaction and productive involvement, and possibly more opportunities for negative influences.

Purpose
There can be changes in the purpose of a person’s daily activities and schedule. Much like the workers of a closed factory, a person who experiences disability following brain injury may have no job to go to and no place to be a “worker.” Similar losses can occur in other life areas such as socialization, community involvement, spirituality, and so on. The resulting problems that we see may be due just as much to the lack of stable and meaningful settings to engage in well-established and personally relevant roles as to the neurological, medical and physical residuals of the brain injury. The early medical challenges of brain injury are often overshadowed by long-standing social barriers.

Some of the changes that we make to adjust our match between the person and the environment and to improve our opportunities are relatively small. We can more easily remember things by using sticky notes or a keeping a date book. We learn which battles to fight and which to ignore in order to keep the peace with our mate or our children. We can change the order of our daily routine in order to do the hardest jobs when we have the most energy. Other changes can be much more dramatic, such as moving to new places, changing jobs, changing relationships, or totally refocusing our lives. However, successfully responding to such changes involves a continual and dynamic balance between many different factors. Challenges following brain injury can make this process even more difficult.

In effect, our environment is the canvas on which we paint our lives. It gives meaning and context to who we are, what we are and the pattern of our daily life. It is just as susceptible to brain injury as the person who experiences the injury or others who are involved with the person. And, just as no two brain injuries are alike, no two environments are alike. Although we may not be able to repair damaged brain tissue, the good news is that we can often change environments to help support a person’s new strengths and reduce the negative effects of persisting challenges. When we do this, functional skills and abilities improve, personal outlook improves and problems are significantly reduced. The results can be dramatic.
Context

Most people seek meaning and balance in their lives, the definition of which varies for every single person. One person’s chaos is another person’s panacea. One person’s peace may be another person’s mayhem. We are all unique and different. Within our abilities, we seek a balance between our interests and our abilities. We seek the resources to support our life styles which in turn affect our opportunities. We seek people and situations that can lift our spirits, make us laugh, teach us or who we can teach, that we can share and benefit from. We try to avoid people and situations that make us angry, depressed, or come loose at all ends. When we are successful, we have balance and harmony. When we are not successful, we often find unhappiness, despair and loss. We learn over time that we cannot control many things and gain a perspective of what is important to us. However, we all have our breaking points where our behavior and composure begin to deteriorate. This often happens when we have lost control and context of our daily lives.

Context is the quality or the manner in which the people, places and purpose of each environment integrates with the individual. It means that the “key” fits the “lock.” Context is just as, if not more, important as the individual pieces.

People

We’ve already spent a good deal of time discussing the range of people who may be in somebody’s life following brain injury. Our key concern here is to determine what the relevance of each individual is to our person of interest. Why are they in this person’s environment?

• Do they “click” with the individual and fit in with that person’s interests, abilities and perspective such as friends, family members, colleagues, etc.?
• Are personally preferred people present when the person is engaged in activities or situations where they can best relate to their friends?
• Is there true reciprocity in the relationship such that both parties benefit from each other on a relatively equal basis?
• Have people been “assigned” to that person based on commonalities of disability rather than shared interests? e.g., “I’d like you to meet Carl here. He also has a brain injury and the two of you may have things in common.” Again, how would you feel being grouped with people because all of you wore glasses, were overweight, were prone to flatulence, or similar commonalities?
• Are they present for a specific purpose, such as aides who supervise someone’s safety, but otherwise have little in common with the individual?
• Or, as we discussed in Chapter 10 on Circles of Support, is no one available?

These distinctions can make a big difference and are significant issues. We are all much more engaged when we have things in common with others and when we can share these commonalities. Our greatest periods of loneliness and awkwardness can occur when we are around many people with whom we have nothing in common. Problems can also occur when people don’t fit in at important times.

Example of misfitting situation:

One young woman was about to be placed in a nursing home because she was not cooperating with the aides who came to her house. She often yelled at them or would not let them take care of her. The problem was that she was very modest and some of the aides who came to wash and clean her were either inconsiderate or males. The problem went away when she was given a say in who was hired to be her aides.

In the workbook exercise, you will be asked to identify the context and relevance of the people who are associated with the person who experiences disability due to brain injury.

Places

Places are the locations where we live, work, play, shop, relax, go to school and carry out life’s other daily activities. Locations need to be both geographically and culturally relevant.

Problems develop when places have little relevance to a person’s life, interests or heritage. Some people live in programs or residential settings that provide shelter, safety, nutrition and medical well-being, but are not located near meaningful social, vocational, educational or community activities. These places may also not provide regular family contact or respect and support a person’s culture and heritage. At a minimum, boredom or withdrawal sets in at such settings. However, far too often, other problems in-
volving self-destructive or aggressive behavior or emotional deterioration occur.

One only has to look back at the history of state institutions for people with psychiatric or developmental disabilities to see the effects of contextually void environments on individual well-being. Many people were housed in such facilities and deemed too sick or impaired to leave. They displayed a wide range of strange or aberrant behaviors in these settings. Yet, many of these same people flourished when they moved into less restrictive and more personally relevant housing and services in their local communities.

Medicaid TBI waivers in a number of states now help some people who experience disability following brain injury benefit from living in their communities, but these funds are limited. Unfortunately, far too many people of greater capacity have to live in nursing homes. These have become the modern day institutions for many people who experience disability following brain injury and have no other resources. It is important to recognize that nursing homes can be important places for individuals with specific needs. However, just like any other setting, they can be “toxic” when people with different capacities and needs are placed there due to a perceived lack of alternatives. Then again, some people are not even this “lucky” and become homeless.

Even people who live at home can become shut-ins when there are no accessible places to meet life’s other needs. Transportation is a major barrier for many people, even those who live in large cities. Many people know of programs and services to meet their needs, but don’t have the time or means to get there. Without the ability to get around, one might just as well be living on an isolated island. People in small towns or rural areas may face problems of isolation due to the distance between different places that support their daily life.

Some basic issues to consider about places include:

Living place
• What type of setting is the person now living in and how relevant is it to their current needs for supervision, safety, mobility, medical needs, behavioral supports, and other supports required for daily functioning?
• How does this living setting relate to the person’s personality? For example, if they have always been a private person, do they have their own room and space or do they have roommates? If they have always been socially outgoing, are there others or personal interests around with whom they can congregate? If the person has always been a loner, do they have opportunities for meaningful solitude?
• Does the living setting support the person’s culture and heritage?
• Does the living setting give the person and their family regular and frequent opportunities for contact if desired?
• Does the person feel comfortable in the living setting?
• Does the living setting promote access to other areas of life interests or create barriers to such access?

Other places
• What other places are available for the person to go to work, socialize, shop, engage in leisure activities, and so on?
• How easy is it for the person to get to these other places on a regular and appropriate basis?
• Does the person have the skills and resources to participate in the activities available within these places? If not, how can reasonable accommodations be implemented?
• Is the person welcome in these other places? If so, is it because of their interests and abilities, or because of their disabilities?
• How does each place fit in with the person’s interests?
• Does the person enjoy being in these places?
• How does the person manage the costs of participating in chosen venues?
• Is the person able to access and use such places at reasonable times of personal need, interest and convenience?
• What special scheduling and organizational strategies are required to facilitate the person’s access to such places?

In the workbook exercise, you will be asked to identify the context and relevance of the places where the person lives and engages in other daily activities.
Purpose

Purpose is often the most important yet most overlooked issue when considering the quality and context of someone’s environment. Simply stated, purpose means that the activities in a person’s day have meaning and value to that individual as well as to their general community, and that they occur at times that are relevant to the person. It is the difference between “going through the motions” of an activity and becoming involved in the activity due to personal needs, interests and/or goals. It is the difference between “keep busy activities” and moving ahead activities.

When there is purpose in people’s lives, people are motivated, more engaged and healthier. When people simply go through the motions, they can become detached from the activities and feel less in control of their lives. Consider the difference between going to a daily “work adjustment” program as compared to going to work or volunteering at something that you like and are good at. Consider the difference of going to a weekly “socialization group” with people you don’t know and going to a ball game with your friends, especially when favorite teams are playing. Purpose is the glue that ties together the person, people and places.

Different people will have different purposes for different reasons. Reasons may range from an enduring relationships, to raising a family, promoting a cause, creating a business, building a house, making music, receiving social attention, and “simply” enjoying life, to “simply” surviving. When activities intersect with purpose, quality of life is created.

Example of purpose and context:

Milton Erickson, a prominent psychotherapist tells the story of meeting a shy and very depressed woman at her home in Minnesota. He was one of a string of psychiatrists and psychologists who had been called upon by her family to treat her with little results.

The interview was labored because of the woman’s reluctance to speak. Taking a break well into their conversation, he noticed an African violet sitting on the window sill. “Do you know how to grow those?” he asked. “Yes,” the woman replied with a thin lipped smile. He proceeded to explain his lack of success with the plant to which the woman explained what he was doing wrong and how he should treat the plants.

The woman became much more animated and expressive as she talked. It turns out that she grew many different types of African violets in her home and spent most of her time with the plants.

Dr. Erickson left the house that evening with a curious prescription. He told the family to build the woman a greenhouse. They did and she grew more violets. Word of her green thumb spread and soon there were people from all over the community coming for advice or to buy some plants. The woman never shied away from talking plants and began to develop a circle of support outside her family. Her depression lifted. Erickson recognized and then helped to expand a vital purpose and context in the woman’s life.

This doesn’t mean that everybody should start a greenhouse, but simply to help people identify their interests and passions. Purposes can also change over time and it is important to keep track of one’s progress and interests.

Example of how purposes can change over time:

A young man suddenly began to run away from a residential program where he had successfully lived for several years. People were puzzled.

On further investigation, it turned out that his purpose and interests had changed while the program had remained the same. At first he was happy to be there when his goal was to live away from home and develop independent living skills. Now that he had completed those steps he was ready to move on, but the program could not adapt. What he once viewed as his refuge had now become his prison. The program had failed to understand that their most important contribution to this individual was to help him grow and not primarily provide him with a roof over his head.

As the individual ran away more over time, the program became more restrictive and the problem got worse.

Moving him to a different location with more things of interest to him, fewer restrictions and greater personal responsibility resolved the problem.

It is absolutely critical to incorporate personal interests and purpose into each person’s daily life. This may not always be easy. Finding or creating such opportunities can be darn well next to impossible. However, steps in this direction will make a substantial and sustaining difference and are absolutely essential! In the workbook exercise, you will be asked...
to identify what the person’s purpose and interests are and how they might be incorporated into their daily environment.

**Ain’t Misbehaving!**

It should come as no surprise that people who have positive context and purpose in their lives generally “behave!” They are generally well attuned and interconnected with people and places of interest and engaged in opportunities and challenges of personal interest. There is balance in their lives and they have the tools to make changes as their lives and environments change.

People devoid of such context will typically do the best that they can. However, it is hard to do much if there are limited opportunities, barriers to “being,” lack of personal involvement, and other missing or distorted factors. For the most part, people under such circumstances are not “mis-behaving” but “behaving” the best they can within mis-arranged or incomplete circumstances. They are functioning within their personal abilities. These abilities, in turn, may be compromised by the effects of brain injury, which in turn, make the person more susceptible and vulnerable to the above noted misaligned environmental factors.

In a classic vicious circle, people and environment can each begin to deteriorate. The less successful a person becomes, the less control and involvement the person may have over their environment, which can cause the environment to deteriorate, which promotes behavioral deterioration, and so on. At some point, people become increasingly frustrated, withdrawn, or otherwise emotionally deteriorate. At that point, restrictive procedures are often inappropriately prescribed to deal with the “behaviorally inappropriate brain injured patient!” Shame on everybody who is involved!! We have to be very sensitive to environmental and contextual factors.

**Summary**

Our environments are complex and play a critical role in determining outcomes and quality of life whether or not we experience disability following brain injury. In this chapter, we reviewed the constructs of person, people, places and purpose. The ways that these factors interact directly affect each person’s behavior and quality of life. Inequities in any of these key factors will result in overall imbalance and the likelihood of behavioral challenges regardless of the presence or absence of a brain injury. Consider how cognitive, perceptual, physical and other changes following a brain injury that reduce a person’s internal locus of control may make a person more vulnerable to environmental influences. Stated another way, everybody needs:

- Somewhere to live
- Someone to love and be loved by, and
- Something of personal and community value to do.

The best way to prevent behavioral problems is to promote success. This will be the basis for the next section of this book.

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**Workbook Exercise**

Please turn to Section 11 of the Workbook. In this section, and with their direct involvement, you will focus on describing the person’s overall environment as it relates to the person, people, places and purpose, as well as the context in which these factors combine to create quality of life.

This section represents the end of the first half of the book. It is a summary of the work you have completed in the book up to this time. It provides the foundation to establish new approaches to address challenging behaviors, which is the second half of the book.

Get as many people as possible to help you with this section as different people will have very different perspectives, especially the person with the injury. Remember, you are only one person in this individual’s circle and others may have very different perspectives.